Connecticut Children's
MEDICAL CENTER

Testimony of the Connecticut Children's Medical Center
to the Insurance and Real Estate Committee regarding
Senate Bill 200 An Act Expanding Health Insurance Coverage for Specialized Formula
March 6, 2014

Senator Crisco, Representative Megna, members of the Insurance and Real Estate Committee, thank you for the opportunity to share my thoughts about *Senate Bill 200 An Act Expanding Health Insurance Coverage for Specialized Formula.* My name is Allison Gomes, and I am the dietitian in the Cystic Fibrosis Clinic at the Connecticut Children's Medical Center and I am submitting this testimony in support of the proposed bill.

Cystic Fibrosis (which is often just called "CF") is an inherited chronic disease that affects the lungs and digestive system. One in every 3,500 infants born each year will have CF, adding to the over 30,000 individuals with CF living in the US. CF causes impaired pulmonary and pancreatic function, which translates to increased work of breathing, increased energy expenditure, increased calorie and protein needs and decreased ability to digest fat without medication. The higher calorie intake needed for those with CF compared to those without CF is about 120-200% more for adequate weight gain and growth. This means that after someone consumes a full dinner, they will need to eat an additional 20-100% more to meet their calorie needs.

The high calorie requirement is very difficult for patients with CF and is a primary reason why enteral nutrition (EN) is so important to prevent malnourishment. Nutrition in CF is very important and is treated as a form of therapy, similar to how breathing treatments and other medications are treated. If you do not meet your calorie needs, it's as if you are only taking your medication half the time.

As these children are entering puberty between the ages of 9-14 years, their need for consistent energy intake for growth is vital. The statute currently limits the coverage of EN in the middle of this important growth and development. EN is expensive and without insurance coverage, families may not be able to afford this vital resource. As a result, these children may not gain weight and grow appropriately. It has been well documented annually by the CF Foundation's Patient Registry Annual Data Reports that achieving a Body Mass Index for age that is above the 50th percentile for children and young adults is associated with maintaining normal lung function. The ability for nutritional status to impact CF is well known and documented in the literature. It has also been well documented that malnutrition and poor growth are associated with reduced respiratory muscle function, increased susceptibility to infection, and with higher morbidity and mortality. Poor weight gain and impaired linear growth are also independent risk factors for early death in CF patients. Long-term nutritional support has been able to improve nutritional status and slow the rate of decline of pulmonary functions.

It does not make sense to take away a life saving resource from these children who are relying on supplemental EN feeds to maintain their nutritional status or who develop the need for EN support after

the age of 12 years. The expanded coverage the proposed bill would greatly impact not only their nutritional status, but also their pulmonary status and quality of life (ie ability to play or maintain employment). The option to continue EN feeds until the age of 26 year allows for CF patients to continue their battle against a progressive lung disease for which there is presently no cure. I urge you to support Senate Bill 200 because extending coverage to age 26 gives these children and young adults an additional tool to fight against Cystic Fibrosis and to live their lives to the fullest extent as any child and young adult deserves.

Thank you for your consideration of our position. If you have any questions about this testimony, please contact Jane Baird, Connecticut Children's Director of Government Relations, at 860-837-5557.

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